

July 2, 2020

Sen. Richard Shelby, Chairman  
Committee on Appropriations  
Room S-128, The Capitol  
Washington, D.C. 20510

Sen. Patrick Leahy, Vice Chairman  
Committee on Appropriations  
Room S-128, The Capitol  
Washington, D.C. 20510

Rep. Nita Lowey, Chairwoman  
House Committee on Appropriations  
H-307, The Capitol  
Washington, DC 20515

Rep. Kay Granger, Ranking Member  
House Committee on Appropriations  
H-307, The Capitol  
Washington, DC 20515

Dear Chairs Shelby and Lowey, Vice Chairman Leahy and Ranking Member Granger:

We, the undersigned national organizations representing all ages and disabilities, are writing to urge funding in the Fiscal Year 2021 Labor/HHS/Education Appropriations bill for the **Lifespan Respite Care Program**, administered by the Administration on Aging, Administration for Community Living. For more than a decade, respite provided by the program has been a vital safety net for the nation's family caregivers of both children and adults. During this pandemic, social isolation among family caregivers has intensified. Respite providers may be their only immediate contact for relief and other critical supports.

We are very appreciative of the increase provided in FY 2020 for the **Lifespan Respite Care Program**. To address the growing need to support family caregivers who are the linchpin of the nation's long-term services and supports system, we are requesting **\$10 million in FY 2021**. This program has received no additional funding from the recent emergency supplementals, yet Lifespan Respite grantees continue to respond to daily requests for respite and have created innovative and flexible new ways to meet caregiver needs during this pandemic.

By adapting consumer-directed respite voucher programs that help family caregivers pay for respite, many grantees and their partners were able to continue to offer respite through enhanced flexibilities. The Oklahoma Lifespan Respite program increased the voucher amount; expanded provider eligibility to include someone who lives with the caregiver and care recipient; and lifted the household income requirement. Virginia instituted similar flexibilities to meet increasing requests for respite since the end of April. In Nevada, Colorado and other states, grantees have extended time limits for voucher use to maximize flexibility in meeting family caregiver needs.

To maintain and expand support to isolated family caregivers in their networks, Lifespan Respite grantees and partners provide support through regular check-in phone calls, connections to food and basic supports, live Facebook events, online support groups, online activities to keep care recipients engaged, home-delivered or mailed care packages with activities for caregivers and care recipients, stress reduction and self-care webinars, and other virtual respite strategies.

Fifty-three million family caregivers, up from 43.5 million just five years ago, provide the vast majority of our nation's long-term services and supports, permitting individuals of all ages to remain in their communities and avoid or delay more costly nursing home or foster care placements. AARP has estimated that family caregivers of adults provide \$470 billion in

uncompensated care annually. Researchers at Boston Children's Hospital found that families caring for the most seriously ill children provide nearly \$36 billion worth of care annually. Their associated foregone earnings were over \$17 billion.

National, State and local surveys have shown respite to be among the most frequently requested services by family caregivers. Yet, 86 percent of the nation's family caregivers of adults do not receive respite. The percentage is similar for parents of children with special needs. For family caregivers caring for someone with Alzheimer's, adults with developmental disabilities, individuals with Multiple Sclerosis (MS), ALS, spinal cord or traumatic brain injury, rare diseases as well as grandparents raising grandchildren and military caregivers, respite is especially elusive. Families caring for children, teens and adults with autism, physical disabilities or mental health conditions also can't find or afford respite.

Lifespan Respite systems, which maximize existing resources, require that respite become more accessible and available to all family caregivers. As importantly, Lifespan Respite systems build respite capacity and improve quality by requiring states to focus on respite provider/volunteer training and recruitment, start-up of new respite services, and affordability issues for family caregivers who struggle financially, but are not eligible for any publicly funded respite services.

We are grateful for the increase the Lifespan Respite Program received in FY 2020 to \$6.1 million. However, additional funding is needed to meet the escalating need, especially in this stressful and isolating time of COVID-19. By investing in Lifespan Respite and other family and caregiver supports, the goal of avoiding or delaying more costly and unwanted institutional care, foster care, hospitalizations and emergency room use, can be reached.

We strongly urge you to fund Lifespan Respite at the modest request of \$10 million. If you would like more information, please contact Jill Kagan at the National Respite Coalition at [jkagan@archrespite.org](mailto:jkagan@archrespite.org). Thank you for your attention to our request and for your support and recognition of the nation's family caregivers.

Sincerely,

ACCSES

Allies for Independence

ALS Association

Alzheimer's Association

Alzheimer's Foundation of America

Alzheimer's Impact Movement

American Academy of Pediatrics

American Association of Caregiving Youth

American Association on Health and Disability

American Dance Therapy Association

American Network of Community Options & Resources (ANCOR)

American Therapeutic Recreation Association

Association of Assistive Technology Act Programs (ATAP)

Association of University Centers on Disabilities (AUCD)

Autism Society of America

Brain Injury Association of America

Caregiver Action Network  
Caring Across Generations  
Christopher & Dana Reeve Foundation  
Division for Early Childhood of the Council for Exceptional Children (DEC)  
Easterseals  
Elizabeth Dole Foundation  
Epilepsy Foundation  
Family Caregiver Alliance, National Center on Caregiving  
Family Voices  
Generations United  
IDEA Infant Toddler Coordinators Association (ITCA)  
The Jewish Federations of North America  
Lakeshore Foundation  
Lupus Foundation of America  
National Alliance for Caregiving  
National Association of Area Agencies on Aging (n4a)  
National Association of Councils on Developmental Disabilities  
National Association of Social Workers (NASW)  
National Association of State Directors of Developmental Disabilities Services  
National Association of State Directors of Special Education (NASDSE)  
National Association of State Head Injury Administrators  
National Council on Aging  
National Down Syndrome Congress  
National Down Syndrome Society  
National Foster Parent Association  
National Military Family Association  
National Multiple Sclerosis Society  
National Respite Coalition  
Pulmonary Hypertension Association  
Rosalynn Carter Institute for Caregiving  
Sibling Leadership Network  
TASH  
The Arc of the United States  
The Myositis Association  
United Cerebral Palsy National  
United Spinal Association  
Well Spouse Association

cc:

Senate Appropriations Subcommittee on Labor-HHS-Education  
House Appropriations Subcommittee on Labor-HHS-Education